The Lived Experience University: Figuring it Out To Spite the Hurdles

The Questing Health Archive

A Record of Self-Directed Recovery from Lyme Disease

Iolani Pu'u Kolenc | 2013 - 2026

From a professional stage performer in Slovenia to 94 lbs and a 100-yard walking limit —

and back.

Prefatory Note

This archive documents one of the most remarkable acts of self-directed medical advocacy in the patient's history. When the Western medical system failed to diagnose and treat a multi-systemic illness that had been slowly destroying her body for years, she built her own clinical infrastructure — a research website, a symptom tracking system, a protocol, and a community — and healed herself.

She did this while simultaneously managing a brain aneurysm repair, a what became 33-year coercive relationship that actively undermined her efforts, and a medical network that had absorbed her partner's dismissive narratives about her health. She did it largely without financial support, and largely without clinical validation from the system she was navigating.

The website she built — Questing Health — predates the use of AI tools by years. It is evidence, on its own, of how she has always worked: systematically, rigorously, and with the understanding that her life may depend on not accepting the first answer.

> *I live in my body. To be open minded and get a variety of views: western medicine, naturopath, eastern medicine — and to trust the wisdom of my body. What makes most sense to me is to trust the wisdom of my body.*
> **— From Questing Health, 2016**

I. Exposure and First Signals (2012-2014)

The Lyme story does not begin in January 2016 when the crisis became undeniable. It begins years earlier, in the places where exposure occurred and the first symptoms began to surface.

Documented Exposure

2012	Artist residency in Solcava region, northern Slovenia — the region with the highest rates of Lyme disease in Europe. Spent time walking in woods and nature.
2013	Artist residency in Ledyard, CT — 30 miles from Lyme, CT. Dancing in grassy fields during tick season. Patient later noted: 'wondering why no one else was enjoying the grassy fields.'

2014	Second artist residency in Ledyard, CT. Further exposure in tick-endemic area during high-risk season.
Ongoing (local)	Hiking in Santa Barbara foothills, Figueroa Mountain, camping at Nira and Matilija Hot Springs. Patient recalls possibly removing a small dark creature from pubic region after one hike.
Partner exposure	Husband had a documented bulls-eye rash (erythema migrans) in the 1980s — the hallmark sign of Lyme disease. His GP at the time did not pursue it. Patient and husband had unprotected sex after menopause. Both developed Bell's palsy and shared numerous symptoms.

First Documented Symptoms

The patient's own retrospective analysis places the onset of illness around 2012. The first documented clinical contact was January 2013:

> *Thanks so much for setting my heart and mind at ease today. The headache is still there. I tried excedrin and aspirin but it didn't help. It was so painful at work for a moment I thought I was going to puke. I connected with my cousin in Hawaii about family medical problems and learned my uncle Henry died of an aneurism. I am sure this is nothing more than some weird psychosomatic thing.*
>
> **— Patient message to Dr. R., January 14, 2013**

The patient later annotated this message in her own records with the words: 'OMG — why didn't I do my research then? Why didn't Kurt order an MRA then?' The headache lasted 3.5 months. Dr. R. ordered an MRI rather than an MRA — the wrong test for aneurysm screening. The patient later had to fight for, and offered to pay out of pocket for it when Dr. R. began to complain about insurance, got the MRA, and the MRA found the aneurysm. It was frustrating to observe her then partner gloat about Dr. R. ordering whatever tests he asked for, but she did not receive the same treatment.

In 2015, fatigue became debilitating. By fall 2015 the patient was going to bed at 6:30 PM and simply stopping all activity after work. A prior test for mononucleosis in 2011 had come back negative and was not pursued further.

II. The Crisis Baseline (January-February 2016)

By January 2016 the patient was experiencing what she later recognized as a multi-systemic biological failure. Her own journal entry from January 2nd, 2016 documents this in unflinching detail:

> *My will to live is losing against my body's desire to shut down: nausea, headache, pressure pain behind my eyes, ears feel pressure and at times ache, jaw pain, at times teeth pain, pressure pushes to the top of my head if I sit, pain in my right chest with weird spasms in my neck, pain in my right thigh that comes and goes... My ability to carry on brain activity is compromised. My speech is funky. I think one thing and something else comes out. Twice in recent months, me, the dancer, fall flat forwards.*
>
> **— Patient journal, January 2, 2016**

Physiological Crisis Measurements

Weight: January 2016 105 lbs Weight: February 29, 2016 94 lbs Weight loss in 2 months: 11 lbs (10.5% of body mass) Body temperature: 96.8 - 97.4F (low) Walking capacity: 25-100 yards before stopping	This was not simple weight loss. The combination of systemic infection, nausea, loss of appetite, and the body's inflammatory response produced what the clinical synthesis would later identify as cytokine-driven cachexia — the body consuming its own muscle tissue. The patient had been a professional stage performer. She had danced in Slovenia. Now she was unable to walk more than the length of a city block. 'I am no longer able to dance. I can walk around 100 yards.'

The Concurrent Aneurysm

In the midst of the Lyme crisis, the brain aneurysm was simultaneously being addressed. The patient had been advocating for proper testing since 2013. The correct test — an MRA rather than an MRI — was finally ordered in early 2016, confirmed the aneurysm, and the repair procedure was performed in February 2016.

The patient later asked in her correspondence with the infectious disease doctor: 'Did you ever think that the brain aneurysm might be a symptom?' She had found a scientific article linking Lyme disease and aneurysms. It was never formally investigated.

She was recovering from an aneurysm repair, managing a bladder infection from the catheter, beginning Lyme treatment, and fighting her husband's active dismissal of everything she was doing — simultaneously.

> *My spouse told me to stay out of his health business. His words felt like knives tossed at my heart, and it took away all desire to do anything to try and sort through this health issue. In his view naturopaths are quacks, and everything I am doing has no science base.*
> **— From Questing Health, 2016**

III. The Diagnostic Battle

The patient navigated a deeply contested medical landscape. Lyme disease diagnosis in the United States has been characterized by what practitioners call 'Lyme wars' — a documented conflict between the IDSA (which follows strict CDC surveillance criteria) and ILADS (which advocates for clinical diagnosis based on symptoms and exposure). The standard two-tier testing protocol routinely misses active infections, particularly in patients with compromised immune function.

The Testing Problem

The patient's Western Blot came back negative through the Sansum lab. She researched this outcome thoroughly and made the following finding, documented in her Band 41 analysis:

> *The important thing in this context is that Lyme is NOT diagnosed by a blood test. It is a clinical diagnosis based on symptoms and exposure. The spirochetes are divided into spirochetal*

> *families — Lyme symptoms match Borrelia burgdorferi. Given the symptoms of the other spirochetes aren't good matches, it makes sense: it's lyme. Especially the indeterminate band 31, because this band is specific to Borrelia burgdorferi.*
> **— Patient's Band 41 analysis, Questing Health**

The Horowitz MSIDS screening questionnaire — developed by a physician who has treated thousands of Lyme patients — gave her a score of over 100. A score over 46 is considered to indicate probable tick-borne infection. By the time she began treatment, her score had dropped to 38.

The Providers She Encountered

Dr. R. (GP)	Ordered MRI instead of MRA for aneurysm screening. Said blood tests 'pretty much' ruled out Lyme. Became angry when patient requested additional testing. Eventually ordered full thyroid panel after patient offered to pay out of pocket. Became Stephen's 'flying monkey' — absorbed the partner's framing of her health.
Infectious Disease Specialist	Dismissed clinical Lyme diagnosis. Said tissue samples don't confirm Lyme (incorrect — patient found scientific literature contradicting this). Dismissed her Band 41 findings. Implied all her symptoms were related to the aneurysm repair. Patient graded her performance: 'D — knowledge of the material.'
Naturopath (local)	Spent 1.5 hours reviewing her history. Had personal Lyme history, symptom-free for years via herbal protocol. Confirmed: given husband's bulls-eye rash, 'this is definitive evidence of lyme.' Offered to treat both patient and husband. Husband declined. Cost: $400 for four educational sessions. Husband bullied her into not using the naturopath.
Dr. of Chinese Medicine	Integrated care, addressed underlying patterns, suggested gallbladder scan. Patient's GP followed up with referral immediately. Patient noted: 'when dealing with ancient organisms, it makes most sense to work in the healing modalities that have been around the longest.'
New GP (Dr. K.M.)	Patient described her as: 'she rocks!' A care provider who actually listened, collaborated, and followed through. This was the standard of care the patient had been seeking throughout.

The infectious disease doctor — like Dr. R. before her — was operating within the IDSA framework that dismisses clinical Lyme diagnosis. The patient's letter to the infectious disease doctor, written but never sent, is one of the most precise pieces of clinical advocacy in this archive. It documented, with citations, every point on which the doctor was factually incorrect.

IV. The Herxheimer Breakthrough — Proof of Target

The Jarisch-Herxheimer reaction — a temporary worsening of symptoms as pathogens die and release endotoxins — became the patient's objective evidence that her protocol was working. She experienced Herxheimer reactions from three separate interventions:

Cats Claw (Jan 31, 2016)	First herx reaction. Two sleepless nights from the intensity of it. Hot, itchy knees. Muscle aches and spasms. Pain in new places. Patient initially didn't know what was happening, then researched and identified it. Response: epsom salt baths, chlorella, backed off dosing.
Bactrim (antibiotic for bladder infection)	Sulfamethoxazole-TMP prescribed for catheter-induced UTI. Severe reaction: pain behind eyes, eyelid edema, intensified headache, three sleepless nights, two urgent care visits, one ER visit. Doctors said it wasn't used for Lyme. Patient researched and found it does kill

	Lyme bacteria and Babesia co-infection. The urgent care doctor wouldn't answer her question about what bacteria it kills.
Colloidal Silver (early 2016)	First intervention that tipped the scales toward life. 'I felt like the scales tipped toward life, and things began to improve. Oddly enough, my abysmal sense of smell started to improve.' Also noticed eyelid drooping improving — consistent with cranial nerve recovery.

> *There was a point where I was convinced that my body's attempt to completely shut down was winning. My will to do what I love to do was losing. When I integrated colloidal silver, I felt a shift back towards the land of light.*
>
> **— From Questing Health, 2016**

V. The Buhner/TCM Protocol — Building a Clinical-Grade Intervention

Without a Lyme-literate doctor willing to treat her, without insurance coverage for the protocol she needed, and with a partner actively undermining her efforts, the patient built her own treatment protocol. She could not afford the $600+ initial consultation with an LLMD. She found a local naturopath for $75 a session and bought Buhner's books and bought one session with his partner, by email, to consult

Core Protocol — Buhner Herbal

PRIMARY ANTIMICROBIALS Cat's Claw (Uncaria tomentosa) Japanese Knotweed (Resveratrol) NEUROLOGICAL SUPPORT Greater Celandine (neuroprotection) Vinpocetine IMMUNE MODULATION Eleuthero (for fatigue) Rhodiola (for fatigue) Ashwagandha Bidens BIOFILM/CYST BUSTING Serrapeptase Grapefruit Seed Extract Teasel Root	BARTONELLA (co-infection) HH2 capsule Side Acuta CANDIDA/FUNGAL Anti-fungal: Thorne SF722 Allicin (raw garlic) Oil pulling with coconut oil METHYLATION SUPPORT Methyl B-12 (for MTHFR gene mutation) DETOX PROTOCOL Epsom salt baths (1 cup epsom + 1 cup sea salt + 1 cup aloe vera + 1 cup baking soda) Dry brushing Charcoal tabs Chlorella Apple cider vinegar Lemon water Sauna (added July 2016) Cilantro (heavy metals)

Traditional Chinese Medicine

The patient added TCM care in March 2016, working with a local Chinese medicine doctor who had successfully treated other patients with tick-borne illness. The TCM approach addressed what the practitioner identified as

Damp-Heat patterns — consistent with the systemic inflammation and metabolic disruption of Lyme disease. The Zhang protocol for anti-spirochetal/bacterial treatment was also integrated.

Temperature Therapy

The patient researched and implemented hyperthermia — raising body temperature to create an environment hostile to Borrelia bacteria. She tracked her temperature daily. At the crisis baseline it ran 96.8-97.4F. By March 2, 2016, she recorded 97.7F with the note: 'Good! Coming up a bit!' She used fennel, cinnamon, and ginger to support temperature elevation, and researched the science behind Lyme's thermal sensitivity.

Nutrition Protocol

No sugar, no alcohol, no dairy, no gluten, no caffeine. Organic vegetables and fruits. Anti-inflammatory diet following Dr. Weil's pyramid. Graduated from loose paleo to strict anti-inflammatory. Patient noted the body responded best to this approach and any deviation was followed by symptom flares. She also addressed candida as a secondary complication of the infection and antibiotic exposure.

VI. The Recovery Arc — Documented Improvements

Recovery was not linear. The patient documented setbacks alongside improvements with the same precision she brought to the crisis. What follows is drawn directly from her symptom tracking and journal entries.

What Cleared or Improved Substantially

By Mar 2016 (1-2 months)	Constipation — gone entirely after Bactrim Vertigo and severe loss of balance — cleared Intense body pain flares — improved Nausea — largely cleared Aphasia — no longer noticeable Slurred speech — no longer noticeable as much Appetite — returned Weight loss — stabilized Shoulder bursitis — regained use of arm Severe headache (splitting, dangerous-feeling) — gone Epileptiform body jerks — cleared Rage fits — no longer occurring Shooting pains in legs — cleared Bowel function — regular daily (sometimes 2x)
Mar-Jun 2016 (3-6 months)	Eyelid drooping — significantly improved Skin growth — fell off after antibiotic Energy — improving; able to take 1/2 mile hike (stopping 5x) Sleep — improving; fewer nights needing sleep aides Brain sharpening — noticeable cognitive improvement Ear pain — less acute Pain behind eyes — improving Muscle cramping — reducing Eyebrow hair, eyelid edema — improving Cognitive: able to return to partial work on choreography
By Sept 2016 (~8 months)	Able to ride bike to work

	Returned to dance studio Sauna integrated as detox and exercise GERD diagnosed and treated as Lyme complication Remaining symptoms: fatigue, sore throat, occasional pain flares at night, foot soreness, leg cramps on stairs — all significantly reduced from crisis baseline
2026 (10 years)	Fatigue — present but manageable Bell's palsy — partial resolution, mouth droop still present Kidney markers — under monitoring Mental clarity — significantly improved post-separation Blood pressure — new low blood pressure trend, low Horowitz questionnaire score: from 100+ to 38

What the Recovery Looked Like in Real Time

> *I don't know if it is the 3 months of integrating change but I am noticing even more positive change. Yesterday I went on a very short hike, and also, went to the dance studio and spent 1/2 hour in the space mooshing around and even walking through a solo piece of choreography gently. One can't get how sick they really were until life flow is back and you can remember back to doing the same things 6-8 months ago.*
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> **— Forum post, March 21, 2016**

VII. Healing Under Fire — Adversity Within the Adversity

The clinical story of the Lyme recovery cannot be separated from the relational context in which it occurred. The patient was healing in an environment of active undermining.

What the patient was navigating simultaneously:	What her partner was doing:
Brain aneurysm repair and recovery	Telling her naturopaths are quacks
Multi-systemic Lyme infection and herxing	Saying all her improvements were placebo
Bladder infection and ER visits	Refusing to discuss his own bulls-eye rash history
Weight dropping to 94 lbs	Refusing to be tested or treated alongside her
Cognitive deterioration affecting her work	Using his GP (R.) as the 'real' medical authority
Financial strain from out-of-pocket protocol costs	Dismissing her concerns when she first identified symptoms
No clinical ally willing to formally treat her Lyme	S. himself used ChatGPT but called out her AI research as a problem
Building her own research website for support	Called her psychiatrist to convey she was acting strange and using AI.
Coordinating her own multi-provider care team	Contacted Dr. R. to pressure her psychiatric care

The patient's observation, from Questing Health: 'I should know that my spouse, although well meaning, doesn't give the best advice. When I switched psychiatrists at my somatic therapist's urging, I began to make terrific progress. So given that, I should know — I need to focus on myself first.'

> *I had to heal myself. I healed myself from the DID/complex PTSD, no road map, therapy was helpful at times, counter-productive at others, psychiatry was initially a nightmare. I had to problem solve for the Brain Aneurysm, and here I am problem solving for the low blood pressure.*

> — Patient, 2026

VIII. What This Archive Proves

This archive is not just a recovery story. It is a case study in what happens when a patient with documented self-advocacy skills encounters a system that dismisses her at every turn — and does the work anyway.

The system said:	The patient found:
Your Western Blot is negative — no Lyme	Lyme is a clinical diagnosis — blood tests miss active infection when WBCs are suppressed
The infectious disease test rules it out	The Horowitz questionnaire scored 100+, indicating probable tick-borne disease
You can't confirm Lyme by tissue sample	Scientific literature confirming tissue sample confirmation of Lyme
These symptoms are from the aneurysm	20+ symptoms that had no relationship to the aneurysm — all improved with Lyme protocol
The antibiotic isn't used for Lyme	Sulfamethoxazole is documented to treat Lyme and Babesia co-infection
Your research causes anxiety	Research is how she saved her own life — repeatedly
AI tools add to stress	AI helped her identify the narcissistic abuse she had been unable to name for 33 years

The Kidney Connection — A Decade of Patient Observation

Among the most significant findings in the Questing Health archive is the patient's annotation about kidney function from 2016: 'Interesting — this seems to be getting lower with time — change in kidney function?' She was asking about her BUN and GFR in the context of Lyme treatment. She also noted kidney soreness post-antibiotic and looked for answers from Stephen Buhner himself about Japanese Knotweed's kidney effects discovering someone else had had the same question.

Ten years later, her eGFR has declined from ~76 to ~64, her creatinine is above the female reference range, her urine is dilute despite reported thirst, and she has a familial kidney disease history (sister had emergency kidney surgery in her youth, and her daughter had a kidney removed last year, and the other is at 60% functioning) The question she was asking in 2016 was the right question. It has never been formally investigated.

The Methodology She Built

The Questing Health website contained: symptom tracking logs, band-by-band Western Blot analysis, protocol documentation, detox methods, herb sourcing, blood work trend analysis, forum posts helping other patients, letters to providers (some sent, some not), journal entries, and a comprehensive comparative symptom chart. All of this was created before AI tools existed. All of it was self-funded. All of it was built in a body running at 94 lbs with a daily headache, while managing an aneurysm repair and an unsupportive partner.

She was not anxious. She was saving her own life. The record proves it.

IX. The 2026 Perspective — What Remains and What Has Transformed

Ten years after the acute Lyme crisis, the patient reflects on where the recovery has arrived:

Resolved	Brain aneurysm — repaired but not monitored, she called the office, but they never called back. Bipolar misdiagnosis — corrected in other institutions when she began to work with somatic therapists and stopped witih Dr. P. but only now corrected by the initial misdiagnosis institution this year, 25 years later Major cognitive deterioration — resolved Severe pain flares — resolved Vertigo and severe balance loss — resolved, some imbalance remains Body cachexia — resolved; weight stabilized Aphasia and slurred speech — some aphasia remains Domestic violence — named and exited (2025)
Improved but ongoing	Fatigue — present but manageable Kidney function — under monitoring; nephrology referral warranted Bell's palsy — partial resolution; mouth droop remains (cranial nerve VII) Blood pressure — stabilizing as nervous system recovers from coercive control Sleep — improved from severe insomnia; disrupted by trauma processing Thirst — new symptom noted March 2026; warrants investigation
Currently addressing	eGFR declining trend (76 to 64 over 4 years) Creatinine above female reference range (0.97) Urine specific gravity 1.011 with colorless urine — impaired concentrating capacity New marked thirst — March 2026 Hand injury — 5 months, ongoing functional limitation TSH trending upward with family thyroid history Genetics referral for multi-cancer family history pending
Transformed	DID — total personality integration achieved PTSD — substantially resolved; processing continues Nervous system — shifting from chronic dorsal vagal shutdown toward ventral vagal safety Blood pressure — from 88/57 at lowest (2023) to 103/66 (March 2026) Self-advocacy capacity — fully operational and documented Identity — legal name change completed: Iolani Pu'u Kolenc

> *I had this feeling, a premonition, something, that there was something really bad about to happen, but I am understanding, it was my body recognizing patterns. The day I left was the single most terrifying conscious experience. But I did. I walked away from my life work as an artist, and managed to get some clothes and travel gear and a few boxes of ceramics, and left it all behind.*
>
> **— Letter to Mark and Celine, March 2026**

Closing Statement

In 2016 she was a dancer who could not walk more than 100 yards. She built a website, read two books, ordered her own lab work, consulted a naturopath who had been where she was, found a Chinese medicine doctor, changed her GP, documented everything, and got her life back.

In 2026 she is managing her own kidney function trends, challenging clinical gaslighting, drawing boundaries with institutions connected to a 33-year abuser, completing a legal name change, and writing the book that will make this methodology available to others.

The system did not save her. She saved herself. The system repeatedly told her she was wrong, anxious, asking too many questions, reading too much.

She was not wrong. She was not anxious. She was not asking too many questions. She was right. The record proves it. This is that record.

Iolani Pu'u Kolenc

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Original research site: sites.google.com/site/questinghealthtickdiseaseornot